

Promoting equality

Response from Department of Health to
the Disability Rights Commission Report,
“Equal Treatment: Closing the Gap”

12th March 2007

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Contact Details	Gary Belfield Director of Programmes, Commissioning Directorate Department of Health Richmond House 79 Whitehall, London, SW1A 2NS
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Introduction

The Department of Health (DH) is committed to the promotion of equality in the NHS, for staff, patients and the public. We are striving to level the playing field. As we continue our reforms towards services that are patient and service user led, it is important now more than ever that we ensure that the needs of everyone in the population are met equally. We are working on many fronts towards this, across the whole equalities agenda: age, disability, gender, race, religion and belief, and sexual orientation. We also have many existing programmes of work, for example, Delivering Race Equality in mental health, a comprehensive programme for tackling racial inequality in mental health care.

This document forms our initial response to the Disability Rights Commission formal investigation and signals our determination to take significant action in the coming months.

On Friday 9th March the Secretary of State for Health ordered an independent inquiry looking at the issues around the standards of care for people with learning disabilities to be set up without delay, following on from the Mencap report, "Death by Indifference". The recommendations from the inquiry will feed into our ongoing programme of work on equality.

The Department's commitment to equality has recently become more explicit in our communications and action. *'The NHS in England: the operating framework for 2007/08'*, published in December 2006, acknowledged concerns over DH and NHS compliance with equality legislation, and reminded NHS boards of their responsibilities. The new NHS principles, published alongside the operating framework and currently undergoing consultation, also highlight our commitment to equality and non-discrimination.

The role of PCTs as commissioners is crucial. Improving commissioning capability is the keystone of health reform, and DH is currently developing a commissioning capability programme. This will focus on improving the strategic approach to health care and prevention, looking at health outcomes over a longer period of time, and reducing health inequalities by narrowing the gap in health outcomes and patient experience.

This drive is supported by the operating framework, which states that, "In particular, PCTs should review how commissioning should be tailored to meet the needs of disabled people, people with learning disabilities, people from black and minority ethnic communities, and people from different gender, sexual orientation and age groups."

SHAs must also ensure they hold PCTs to account, along with the Healthcare Commission. Local Involvement Networks aim to empower all citizens and give them more opportunities to influence the health and social care system,

and promote public accountability through open communication with commissioners and providers.

In preparing this response we have sought to provide an honest account of policy and our aspirations for each recommendation made. We acknowledge that the issues raised are complex and require the engagement of a wide range of stakeholders, some of whom have traditionally not been well engaged in the healthcare of people with learning disabilities and mental health problems. This response is the beginning of a programme of work. A steering group, led by the commissioning directorate, will undertake a programme of work across the range of recommendations, in partnership with the DRC, to embed equality in the Department and NHS.

Response to recommendations

Recommendation 1:

Governments in England and Wales should make closing these gaps of health inequality part of their departmental objectives

We agree that health inequalities must not be allowed to persist, and tackling health inequalities is a major Government priority. Health inequalities is included in the top six priorities for the NHS for 2006/07¹, and is a main motivation behind the recent Government White Paper². Strong expectations for concerted actions are also placed on the NHS and local government by the Operating Framework for 2007/08³ and the Commissioning Framework for Health & Well-being⁴.

Recommendation 1a: Strengthen guidance for commissioners to ensure services effectively meet the health needs of the whole population

We agree that further guidance for commissioners is required. DH published on 6 March 2007 a “Commissioning Framework for Health & Well-being”, which will guide commissioners on effective commissioning for improving health and well-being and providing services outside of hospital. It is intended to improve the quality, coordination and integration of services, and promote health, well-being and independence for the whole community⁴.

The consultation on the commissioning framework includes specific activities across England targeted at reaching groups that can be hard to engage, including organisations representing people with learning disabilities and mental health problems. Users, carers and patients were engaged in the Our Health, Our Care, Our Say consultation – the Framework consultation is more technical and is aimed at commissioners and providers.

An important part of this document is improved assessment of the needs of the whole population and individual people. The Commissioning Framework for Health and Well-being consults upon a new duty on PCTs and Local Authorities of joint strategic needs assessment. The document is also consulting on a minimum dataset to be used for these assessments.

¹ “The NHS in England: The Operating Framework for 2006/07”, January 2006

² “Our Health, Our Care, Our Say” white paper, January 2006

³ The NHS in England: Operating Framework for 2007/08, December 2006. The Operating Framework sets out the ‘rules’ for the NHS for the year ahead, focusing on the top Government priorities for improvement

⁴ The framework complements the “Health reform in England: update and commissioning framework”, issued in July 2006, which focused on hospital services

Commissioning: Commissioning is the means to secure the best value for local citizens. It is the process of translating aspirations and need, by specifying and procuring services for the local population, into services for users which:

- deliver the best possible health and well-being outcomes, including promoting equality
- provide the best possible health and social care provision
- achieve this within the best use of available resources.

Recommendation 1b: Include incentives in the GP contract for evidence-based regular health checks for people with learning disabilities and/or enduring mental health problems, in line with evidence of need. Their outcomes should be audited in terms of quality and subsequent treatment

We agree that health checks are the most effective way to improve the health of people with learning disabilities or mental health problems.

Mental health patients

The Quality and Outcomes Framework already includes an indicator that rewards practices for providing an annual review for patients with schizophrenia, bipolar affective disorder and other psychoses. Through the review the patient should be offered appropriate routine health promotion and prevention advice for their age, gender and health status.

The physical health review should normally include:

1. issues relating to alcohol or drug use
2. smoking and blood pressure
3. cholesterol checks where clinically indicated
4. body mass index
5. an assessment of the risk of diabetes from olanzepine and risperidone⁵
6. cervical screening, where appropriate

PCTs are responsible for verifying that practices meet quality clinical standards when using the QOF and for supporting practices in continuously improving quality. Practices are required to report the percentage of patients on the mental health register that have been reviewed in the previous 15 months. Verifying that these checks have been done may involve random selection of patient case records to confirm that the annual review was undertaken and correctly recorded.

Quality and Outcomes Framework (QOF): part of the General Medical Services (GPs) contract that resources and rewards GPs for how well they care for patients (to consistent clinical standards) rather than simply how many they treat.

Learning disabled patients

⁵ Anti-psychotic drugs (mostly for schizophrenia) that have been associated with increased risk of developing diabetes

DH remains committed to introducing regular, comprehensive health checks for people with learning disabilities. We believe introducing health checks is a vital step as the evidence shows these are the best way to improve the health of people with learning disabilities. PCTs have a vital role in ensuring that health checks are undertaken. The Department of Health has commissioned the NHS Primary Care Contracting Team to develop a primary care service framework, which will help PCTs commission health checks for people with learning disabilities in general practice. This will be available in 2007/08. In future contractual negotiations with GPs, one of our priorities will be access to regular healthchecks for people with learning disability.

Practices are now being rewarded for the first time for setting up a register of patients with learning disabilities⁶. This will help primary care provide better and more appropriate services for people with a learning disability. It should also help planning services for people with complex support needs, and make it easier to link with specialist health services for people with learning disabilities.

Recommendation 1c: Ensure screening programmes are targeting in line with evidence and are fully inclusive of people with learning disabilities and/or mental health problems

We agree that screening programmes must be fully inclusive. Screening programmes in England are based on the latest evidence and meet internationally recognised criteria for the condition, the test used, the treatment options and their effectiveness and its acceptability to the public. Screening programmes are planned to include all groups, including people with learning disabilities and/or mental health problems.

NHS screening programmes must be proactive to ensure that vulnerable groups do not miss out on screening. They are expected to follow good practice guidelines which are set to ensure the programmes are fully inclusive. They are also expected to review take up rates for screening and should take steps to maximise accessibility. Materials are produced to assist screening programmes in ensuring that they are accessible to people with disabilities⁷.

PCTs, in their commissioning role, have a responsibility for the health and well-being of their whole population. This includes assuring themselves that screening programmes are targeting the whole eligible population. We will be writing to PCTs to remind them of this obligation shortly.

The National Screening Committee, which oversees all screening programmes in England, will look again at equality of access to screening programmes and rates of uptake and will work to ensure that good practice guidelines on equality are followed by all screening programmes.

⁶ QOF revisions for 2006/07

⁷ Two examples are "An Easy Guide to Breast Screening for Women with a Disability", DH, March 2006 & "An Easy Guide to Cervical Screening for Women with a Disability", DH, March 2006

Recommendation 1d: The national bowel cancer screening programme in England should ensure eligible people with schizophrenia are offered screening on an equitable basis and should in future consider prioritising them as a high-risk group

DH agrees that the eligible population should be offered screening for bowel cancer on an equitable basis, regardless of disability or other characteristics. We are developing materials on bowel cancer screening, similar to the ones mentioned in the response to 1c, to assist local screening programmes in ensuring their accessibility. We expect local screening services to monitor uptake rates for bowel screening in the same way as those for other screening programmes.

We are currently in the process of setting up a Ministerially-appointed Bowel Screening Advisory Committee. In providing advice to Ministers and DH on the development of bowel cancer screening, and monitoring its effectiveness and efficiency, the group will consider the screening of high risk groups. Any decisions on targeting of screening will be based on robust scientific evidence and further research is needed to confirm the new finding that bowel cancer is more common in schizophrenics and to investigate possible causes.

Recommendation 1e: Take action where access to primary care is a problem for particular populations – ensuring there is a national system for people without a permanent address to register with a GP and that charges in residential settings for receiving GP services are not passed on to residents

We agree that access to proper primary care is essential for everybody.

Registration with a GP practice for those without a permanent address

PCTs have a duty to secure NHS primary medical services for their local population. PCTs have contracts with practices to provide services for registered patients, who live within the practice 'catchment area'. It is possible for those without a permanent address to register with a GP, by using, for example, the practice's address. PCTs and practices were last reminded of these provisions in 2003, and so DH will issue further advice in 2007.

We do not agree that a national system for those without a permanent address to register with a GP is necessary or appropriate. The problem is not evenly spread across the country, and manifests itself differently in different areas. PCTs are expected to address problems locally, by working in partnership with the community. DH will issue examples of good practice alongside the refreshed guidance.

Charging care homes residents for primary medical services

We agree that further action may be needed by DH on this issue. Care home residents, like the rest of the population, are entitled to free primary medical services. DH will continue to remind SHAs, PCTs and practices of this.

We are aware that some care homes enter into contracts with GP practices to provide additional care, beyond that which is covered by primary medical services. For example, the care home may enter into a contract with a GP to provide an exclusive on-call service for residents. These are private arrangements and practices are entitled to charge either the care home or resident. However, the process and contract must be transparent. We are also aware of reports that GP practices have removed patients from their list, following classification of their residential home as a private hospital⁸. DH is currently collecting information on the incidence of these problems and examples of best practice. We will then develop further guidance for discussion with the BMA and care homes representative organisations.

Recommendation 1f: Spearhead (with partners) medical and nursing training that explicitly tackles 'diagnostic overshadowing' and unequal treatment, at undergraduate, postgraduate and continuing professional development levels. They should incentivise training through the GP appraisal system

We agree that diagnostic overshadowing can lead to poor healthcare. DH will work with the NHS, the sector skills council for health and social care, regulatory bodies and education commissioners to consider how to address 'diagnostic overshadowing' in educational training and standards and ensure that training underpins fair and appropriate treatment.

DH will be reviewing NHS appraisal systems, in light of a recent consultation⁹. This will allow a closer link between development needs and professional and educational standards.

We will also, through our links with local self advocacy groups, explore ways to increase their capacity for developing and running local training programmes for NHS staff.

Diagnostic overshadowing: the tendency to attribute all problems to the person's disability, without exploring other reasons for physical or mental health problems

Recommendation 1g: Consider requiring receptionists to hold specific competencies, working with the Association of Medical Secretaries, Practice Managers Administrators and Receptionists (AMSPAR) and the British Medical Association (BMA)

We agree that it is important that all practice staff understand the needs of disabled people. DH is currently working with the DRC, BMA, AMSPAR and the sector skills council for health on a national framework that will improve the disability education and knowledge of all NHS and social care staff. The document will be published in Spring 2007.

⁸ There are reports that some residential and nursing homes have been classified as private hospitals for the purposes of the Care Standards Act 2000. GP practices may then remove these patients on the basis that they cannot be resident at a hospital.

⁹ Chief Medical Officers "Review of Medical Revalidation: A call for ideas"

DH will write to each of the health professional regulatory bodies to inform them of the DRC report's recommendations and our responses. We will work with these bodies to address diagnostic overshadowing and unequal treatment in their undergraduate curricula.

Recommendation 1h: Centrally target these very high risk groups in national health inequalities programmes

The national health inequalities programme is based on a national target¹⁰, and necessarily focuses on the fifth most deprived areas (the 'Spearhead' group) where the life expectancy is lowest. Within these areas, PCTs adopt a targeted approach to those people most at risk. Work is currently ongoing to consider how a future Health Inequalities target beyond 2010 could be formulated, and how this could ensure that high-risk and disadvantaged groups across England are targeted.

All PCTs have a responsibility to commission health services for the whole local population, using strategic needs assessments. We are currently consulting (through the Commissioning Framework for Health and Well-being) on reinforcing this by introducing a new duty of Joint Strategic Needs Assessment on PCTs and LAs. The NHS Operating Framework 2007/08 reiterated the importance that these assessments ensure the needs of disadvantaged or high risk groups, including people with learning disabilities, are met.

In addition to these requirements we have now set mandatory targets for all PCTs and Local Authorities to deliver reductions of their within-area health inequalities, focusing on all-age all-cause mortality. To deliver this, PCTs and local authorities will put in place a range of interventions to reduce the gap in life expectancy within their populations, based on local needs assessments, the evidence base and local intelligence. PCTs are recommended to undertake a health inequalities impact assessment to ensure that the needs of the whole population, including those with a disability, are fully considered.

In December 2006, the Department of Health undertook a review of all its Health Improvement Programmes to ensure that they properly address the needs of people in high-risk and disadvantaged groups. As a result of this review the Department has identified a number of additional partners with whom to work to ensure greater access to health improvement programmes. For example, the Physical Activity programme is now working with the Inclusive Fitness Initiative to ensure wider availability of fitness facilities for people with both physical and learning disabilities.

Recommendation 1i: Require that the Care Programme Approach (CPA) and unified assessment should include access to primary care, achieved to Quality and Outcome Framework standards; and access to health promotion and health checks

¹⁰ A PSA target to reduce the life expectancy gap by 10% by 2010 between people in the fifth most deprived ('Spearhead') areas and the average for England.

We agree that the Care Programme Approach has the potential to drive further improvements in the physical health care of people with severe mental illness. DH and the Care Services Improvement Partnership (CSIP) are currently consulting on the CPA¹¹, asking what more can be done to ensure that the physical health needs of mental health service users are met. The consultation period ended in February 2007, and our intention is to publish updated guidance later in 2007, for implementation from April 2008.

Care Programme Approach: a case management system for people with mental illness who are using specialist psychiatric services, established in 1991. It coordinates an individual plan covering health, care, housing, finance, education and personal aspirations

Recommendation 1j: Improve the participation of people with learning disabilities and/or mental health problems as leaders in health service organisations

We agree that disabled people should be employed as leaders in the health service. DH recently launched a drive to encourage employers to sign-up to a set of anti-stigma principles¹². These include demonstrating that they have made changes in their work environment and employment practices to ensure everyone is treated fairly and equally. The NHS and other public service organisations will be the first organisations targeting in this drive.

In May 2006, Nicola Smith, who is learning disabled, was appointed as the new tsar for people with learning disabilities to help lead government policy. She works alongside the current National Director for Learning Disabilities, Rob Greig, and co-chairs to Learning Disability Task Force.

For more on Local Involvement Networks, which will strengthen the voice of people with learning disabilities and mental health problems, see recommendation 3d. For strengthening the role of NHS Boards, including board level appointments of people with learning disabilities, see recommendation 5a.

Recommendation 1k: Support a partnership of people with learning disabilities and/or mental health problems to spread knowledge on rights. This should include a package of information on how to negotiate for improved services and questions to ask in primary care, which can be easily downloaded and provided to service users when needed

We agree that service users with learning disabilities and/or mental health problems need more support and information to get the most out of primary care.

¹¹ CSIP consultation document: Reviewing the Care Programme Approach, November 2006

¹² 'Action on Stigma', October 2006.

We will strengthen Health Action Plans for people with learning disabilities through new guidance. This will include the role of primary care professionals and specialist services.

A community interest company has been established to market and deliver the Expert Patients Programme and extend the number of available course places to 100,000 by 2012¹³. The EPP is a peer-led self-management programme for people with long-term health conditions. It supports people to develop skills to better manage their conditions on a day-to-day basis and improve their quality of life. The course is being adapted to make it more accessible and responsive to the needs of people with learning difficulties, with the advice of an expert advisor. The pilots will take place in January 2007 with the programme for people with learning disabilities to be rolled out during 2007.

DH has developed, with stakeholders, a generic set of questions and tips to support people in getting the most from their appointments with professionals. The format and design of the 'power questions' are currently being tested with a range of groups, including people with learning disabilities and mental health problems, to ensure they are fully inclusive. The questions should be available from March 2007.

We will explore ways to capture and build on existing good practice through the Valuing People Support Team and Care Services Improvement Partnership. We will also encourage the development of Total Communication Networks, which promote the use of accessible information locally.

Recommendation 11: Set standards and use inspection, scrutiny and performance management frameworks to verify that organisations are meeting standards and using the DED positively to promote disability equality in relation to mainstream health priorities

DH has recently produced guidance for the NHS on ensuring disabled people get equal treatment to everyone else¹⁴. The document covers issues such as involving disabled people, mapping services, assessing policies for disability issues and using remedial action to improve the situation. We will produce a supplement to this guidance specific to learning disability, to help the service when developing Disability Equality Schemes. DH is currently reviewing its PSA targets to ensure they do not discriminate against disabled people (or any other group).

The DH Action on Stigma programme is an important contribution to compliance with the DED. It comprises a robust set of principles and associated action (including information and training) designed to tackle discrimination on the grounds of mental illness, both in the workplace and in the provision of services. We have been clear that we expect NHS organisations to be at the forefront of implementing the programme.

¹³ This commitment was outlined in 'Our Health, Our Care, Our Say', January 2006

¹⁴ 'Creating a Disability Equality Scheme: a Practical Guide for the NHS', October 2006

NHS and social care organisations are responsible for ensuring that they are compliant with the Disability Equality Duty. Any shortcomings will be picked up through the inspectorates, and by the Disability Rights Commission themselves.

DH will explore the possibility of developing an induction training package for new NHS staff on the Disability Equality Duty.

DED: The Disability Equality Duty, which came into force on 4 December 2006, places a duty to promote disability equality on public sector organisations. All public sector organisations have to publish a Disability Equality Scheme and act on it to comply with the duty.

Recommendation 1m: Ensure these groups get full and equal benefit from any new developments, by subjecting proposals to Disability Equality Impact Assessments

DH has introduced a 'Single Equality Scheme', so that all developing policies are assessed for their relevance to equality. This will happen simultaneously for race, gender, age, disability, faith and sexual orientation. An equality impact assessment tool is available to assist all staff, which is available on the DH intranet. The impact assessment process includes the recording of details of how disabled people have been involved in policy development. The Department's systems and processes are being revised to ensure that the scheme is used, and it will be informed by the Action on Stigma programme described above.

Recommendation 1n: Produce a timeline explaining proposed actions by the Department of Health

We agree that an action plan is a helpful way of summarising the work that DH is committed to following this response. It can be found at Annex A.

Recommendation 1p: Progress should be tracked by breaking down PSA targets in England (like early death from CHD or cancer) by broad impairment group – so we know who is dying young from CHD or cancer over time. The Secretary of State for health should report on progress in tackling health inequalities as part of their Secretary of State duty under the DED

We do not agree that breaking down national targets, as described above, is an appropriate or effective way to monitor trends in healthcare quality and access for specific user groups. DH is committed to moving away from measuring performance using national targets, in line with the rest of Government. PCTs are accountable locally to the population whose health services they commission. It is therefore the responsibility of the PCT to reflect their local population when commissioning services, and to monitor trends in health, healthcare quality and access, and to respond appropriately. It is likely PCTs will need to collect data locally to meet this responsibility, as well as auditing service utilisation and responding robustly where problems

are identified. DH will support SHAs in their role of ensuring PCTs do this properly.

However, we recognise that there is a need for better metrics to support commissioners in meeting the needs of people with mental health problems or learning disabilities. The Department's strategy for improving Public Health information and intelligence, to be published shortly, will make recommendations to address deficits in the available data, which, when implemented by local providers, will allow improved monitoring of progress by population group.

In addition, as part of our delivery of existing PSA targets, DH will explore ways of establishing the mortality rates for conditions with known inequalities (such as cardiovascular disease) of people with mental illness or learning disability.

Recommendation 2:

Commissioners of services (practice based commissioners, Primary Care Trusts, Local Health Boards and local authorities) should analyse the physical health needs, experiences and views of people with learning disabilities and/or mental health problems as part of their local strategic assessments of needs; and use this data directly to commission services to close gaps of inequality

We agree that strengthened commissioning is the key to improving services. Good data and information, including the views and experiences of people with learning disabilities and/or mental health problems, is one part of the picture. A programme of work to strengthen the skills of PCTs as commissioners, currently being scoped by DH, will also contribute.

Recommendation 2a: Identify groups who may need outreach or new service models to ensure they get primary care, to at least the same standard required for everyone (for instance, people in residential and hospital provision receiving primary care to Quality and Outcomes Framework standards)

We agree that the needs of all groups must be met when commissioning primary care services.

Recommendation 2b: Ensure the views of people with learning disabilities and/or mental health problems are used to drive actual improvements in service, through public and patient involvement. They should also ensure service users are welcomed and supported to participate in patient and public involvement initiatives including patient forums, expert patient programmes, Community Health Councils (in Wales) and patient surveys. This may require targeted focus groups and production of accessible materials.

We agree it is important everyone has a voice, and that services respond effectively to patients. In 2001, DH introduced a number of bodies to ensure the views of people with learning disabilities were heard¹⁵. The local Learning Disability Partnership Boards help to join up the work of different public services and encourage participation of people with learning disabilities and their carers, as well as monitor how health services are commissioned locally. The Learning Disability Task Force will commission some research in early 2007 to find out what the barriers are for partnership boards, with a view to strengthening their role.

¹⁵ Valuing People led to the creation of the Learning Disability Taskforce, local Learning Disability Partnership Boards, the Valuing People Support Team and the National Forum of People with Learning Disabilities (a forum composed entirely of people with a learning disability that operates at a regional level)

The Care Services Improvement Partnership (CSIP) aims to build and support a strong voice of people who use services and their families in all the work they do, through a programme called 'Having a Voice'. This programme works to make sure that:

- there are clear ways of working with people who use services and family carers, and people know how they can be involved
- there is support for people to have a strong voice and grow as leaders
- there are work programmes to support other organisations to give service users and carers a voice
- good practice on giving people a strong voice is shared

Local Involvement Networks (LINKs) will have an important role to play in ensuring everyone has a voice (see recommendation 3d). 'Having a Voice' is working closely with DH and the Commission for Patient and Public Involvement in Health as the new arrangements for LINKs are developed. A central consideration is to ensure that LINKs are able to involve a diverse range of people with different experiences.

Recent guidance published by DH¹⁶ advises commissioners on involving people with mental health problems in the development, delivery and evaluation of health improvement programmes. We are committed to funding an advocacy service for people with mental health problems, provided by the voluntary sector, and focusing on health promotion and access to healthcare.

Advocacy: speaking on behalf of someone whose voice is not always heard, usually to argue for (or against) a particular idea or policy.

Recommendation 2c: Commission new service models and evidence-based collaboration, between primary care and voluntary sector or specialist services such as Community Mental Health Teams (CMHTs)/Community Learning Disability Teams (CLDTs) and residential services, to improve access and day-to-day support on physical health by those in touch with service users

We agree that an innovative approach to service delivery can improve health care for disabled people. DH recently proposed new approaches to the management of physical ill-health among people with mental illness¹⁷, such as a specialist team working with primary and social care. Pilot programmes that were led by a mental health nurse succeeded in encouraging significant and sustained reductions in smoking, alcohol intake and weight, and in promoting physical activity and self-esteem. DH has made funding for similar projects available to the most deprived parts of the country¹⁸.

¹⁶ "Choosing Health: Supporting the physical health needs of people with severe mental illness", August 2006

¹⁷ "Choosing Health: Supporting the physical health needs of people with severe mental illness", August 2006

¹⁸ The funding has been made available to Spearhead areas, which account for over a quarter of the population. These areas have the fifth worst health and deprivation status in the country.

Recommendation 2d: Ensure healthy living support is targeted at people with learning disabilities and/or mental health problems and their families and that they can be involved in designing their individual health promotion programmes

We agree that health promotion messages should reach the whole population. Responsibility for commissioning health services rests with PCTs, and DH expects that to include appropriate healthy living support for the whole population. DH expects that this will include health action plans for learning disabled patients. These should contain details of healthy living support and access arrangements, and be prepared in consultation with the user. SHAs must ensure that this function is effectively carried out as part of a mainstream performance conversation, and any locally-raised concerns are addressed.

The substantial role of carers in supporting the well-being and health improvement of disadvantaged citizens is well known and has long been recognised by government. DH intends to build on and develop this role by establishing an 'Expert Carers Programme (ECP)', to train carers to enable them to better manage their needs, and the needs of those they support. Work to develop the programme is ongoing, and has involved national carers' organisations. We hope to launch the ECP in 2007/08.

Recommendation 2e: Build robust disability access and quality standards into all contracts with providers, in the public, private and voluntary sectors. Healthy living standards should be included in contracts: for instance, it should be possible for users of residential or hospital services to eat the recommended five portions of fruit and vegetables per day and take the recommended levels of exercise

We agree that building standards on access and quality, amongst others, into contracts between PCTs and providers is good practice that all PCTs should follow. The national model contract, recently published by DH to improve the quality and consistency of PCT contracts, will require all providers of health and well-being services to comply with the law, including the Disability Discrimination Act. PCTs are expected to set local standards for quality improvement to reflect local priorities. DH will monitor this process, and review whether it is necessary to set national standards for quality improvement from 2008/09.

The 'Commissioning Framework for Health and Well-being' (see answer to 1a) sets out how local commissioners (PCTs, LAs, children's trust arrangements etc) should work together to commission to support health, wellbeing and independence for all individuals in their local area.

Recommendation 2f: Track GP allocation requests to spot any potential discrimination on grounds of disability or race

We do not agree that this recommendation would provide information to allow us to spot discrimination. PCT's use of patient allocation varies across the country. Although it is intended to help patients secure registration where local practices have 'closed' lists (due to capacity problems), some PCTs use this process to assist the patient in registering regardless of whether lists are

'open' or 'closed'. In the latter case, assignment of patients to a practice is not necessarily an indicator of a problem. DH abandoned (in July 2006) the collection of monthly data on the number of people allocated by PCTs to practices, as it was not offering meaningful information.

Recommendation 2g: This will require strengthening capacity and expertise in mental health and learning disability. Progress should be tracked by monitoring trends in morbidity, survival rates, diagnosis, condition management and patient experience

We agree that commissioners of primary care services need a better understanding of the needs of service users with a mental illness or learning disability. This will involve making optimal use of local information to identify these needs more accurately and assess the effectiveness of intervention, regardless of condition or disability (see response to 1a).

In November 2006, David Nicolson, the NHS Chief Executive, wrote to SHA chief executives, copied to PCTs, advising them to ensure their organisation had sufficient skilled commissioning capacity for learning disability services¹⁹. At the same time, the Secretary of State for Health wrote to SHA chairs, asking them to support their Chief Executive in this process.

DH recently advised PCTs²⁰ that physical health improvement programmes for people with mental health problems needed to evaluate and review the programmes' effectiveness by gathering data including patient reports of health checks and lifestyle assessments, improvements and actions, and referral and follow up procedures.

At a national level, DH will discuss obtaining data on the causes of death of people in contact with mental health and learning disability services with the Office of National Statistics. The Healthcare Commission's patient survey programme will continue to monitor the experiences of patients in a variety of settings, including primary care and mental health care.

¹⁹ This letter was in response to the joint Healthcare Commission and Commission for Social Care Inspection investigation into the provision of services for people with learning disabilities in Cornwall

²⁰ Choosing Health: Supporting the physical health needs of people with severe mental illness"

Recommendation 3:

Primary care providers should improve equity of access and treatment

Primary care providers must ensure that their services are accessible to all. See response to 2e on ensuring access requirements are built into contracts between PCTs and providers.

Recommendation 3a: Offer people with learning disabilities and/or mental health problems the option of recording their access needs so they appear on patient records and can be easily identified and met. The primary care provider should offer a range of personalised adjustments including different appointment lengths, first or last appointments, text or telephone appointment reminders, accessible appointment cards, telephone consultations and specific waiting arrangements

We agree that it might be desirable to mandate specific improvements in equity of access for people with learning disabilities or mental health problems. DH will explore this possibility with NHS employers, in the first instance.

Recommendation 3b: Offer regular evidence-based health checks and close monitoring of the physical effects of any psychiatric medication to people with learning disabilities and/or enduring mental health problems

For response to evidence-based health checks see 1b.

Recommendation 3c: Take extra care to ensure these groups receive the health promotion, screening and physical treatment they require, as well as information and choice in relation to physical effects of psychiatric medication

We agree that people with learning disabilities or mental health problems should receive high-quality primary care, and be provided with information and choice on the effects of psychiatric medication.

For more on health promotion, see response to 2d.

Primary care providers must offer their patients information and choice around the medication they provide for any illness, including mental illness²¹. The responsibilities of both primary and secondary with regard to the physical health of people with mental health problems are set out in clinical standards guidelines²², and include providing information on the physical effects of the medication and offering an informed choice of medication. DH will discuss with the appropriate Royal Colleges and other agencies what more needs to be done to ensure doctors have the information they need.

²¹ "Good practice in prescribing medicines", General Medical Council, 2006

²² The National Institute of Health and Clinical Excellence guidelines on schizophrenia, depression and bipolar disorder.

Recommendation 3d: Make direct contact with local disability groups and involve them in advising on improvements, for instance through delivering training to the whole primary care team so that everyone from receptionists, to practice managers and GPs engage in improving systems

The new Local Involvement Networks will include disabled people, and be made up from user groups, local voluntary and community organisations and interested individuals. DH will be stressing, through guidance on setting up these networks, the importance of ensuring that all groups are involved, particularly those with learning disability.

LINKs will make recommendations to both commissioners and providers on improving their services. They will also gather and analyse information from a wide range of people and sources and identify and pass on trends and concerns.

Local Involvement Networks: LINKs are a flexible way for groups of people to engage with the health and social care system, strengthening the public voice. This will help promote accountability of the NHS to the local community.

Recommendation 3e: Give anyone removed from a GPs list or refused access to a list written reasons why, in line with existing guidance

We agree that practices must provide reasons for excluding or removing a person from the registered list, as required by existing regulations. GPs may only refuse an application, or have a patient removed, on reasonable grounds that do not relate to disability or any other characteristic. Practices must then notify the patient concerned of the reasons and keep a written record of the reasons, which must be made available to the PCT on request. Patients should receive a warning before removal from a practice list, unless an extreme incident occurs (such as violence towards a member of staff or other patient that is reported to the police), in which case patients may be immediately removed. PCTs must notify patients of their acceptance onto or removal from a practice list.

The enforcement of these provisions is a matter for SHAs. DH will explore ways of raising the priority attached to this aspect of PCT performance.

Recommendation 3f: Progress can be tracked by including people with learning disabilities and/or mental health problems and their organisations in patient and public involvement initiatives and surveys

We agree it is necessary to track progress in involvement of people with learning disabilities and mental health problems in shaping their health services. Patient experience is a key measure of the performance of health services. Surveys of service users are a well-established feature of regulation of the health service in England. When done well, these surveys can be used to compare the experience of different groups in different organisations over time.

The Healthcare Commission²³ administers a range of surveys on behalf of DH, and analyses the results by group. It currently collects self-reported data on whether respondents have a physical or mental health problem or disability. We do not currently identify learning disability as a separate subset, but we will discuss including this in future surveys with the Healthcare Commission.

DH recognises that current surveys under-represent the views of some people, including those with a learning disability and mental health problem. The Healthcare Commission have commissioned a report that will look at the best way of ensuring, through survey design and cognitive testing, that the views of black and minority ethnic and disabled people are taken into account. The work should be completed in time for the 2007/08 surveys programme.

²³ The organisation that regulates the health service in England

Recommendation 4:

Specialist mental health and learning disability providers should support people with learning disabilities and/or mental health problems in accessing primary care and taking care of their physical health

We agree that specialist providers have an important role to play in ensuring that their service users also get proper access to primary care and support to look after their physical health.

DH will shortly produce guidance on commissioning 'Specialist Disability Services', in order to clarify the roles and responsibilities of these service providers, including on enabling access to mainstream primary care. The guidance will also support a person-centred approach to Health Action Planning.

See response 1i on the Care Programmes Approach for people with a mental health problem.

Recommendation 4a: Ensure through care plans and health action plans that service users can access primary care to Quality and Outcome Framework standards and give service users copies of their plans

We agree that all service users should receive primary care to the same (QoF) standards.

The current review of the Care Programmes Approach will be exploring what more can be done to improve the physical health of people with mental health problems (see response 1i).

We expect primary care staff to engage with the government policy of health action planning for people with learning disabilities. Health Action Plans should be completed to the appropriate clinical standards. We will be strengthening Health Action Planning guidance to help facilitate this.

PCTs must (since 4 December 2006) publish a Disability Equality Scheme showing how they are going to meet the Disability Equality Duty, and ensure that their contractors, including GPs, are aware of and fulfil their responsibilities to disabled people under the duty.

Recommendation 4b: Prevent inappropriate prescribing of psychiatric medication and inform people of benefits and risks

We agree that inappropriate prescribing of psychiatric medication is not acceptable clinical practice. Clinical standards guidelines set out responsibilities of clinical staff regarding the prescribing of psychiatric medication (see response to 3c). We will discuss possible further action with the Royal Colleges of Psychiatry and Nursing.

Evidence has shown a substantial over-use of psychiatric medication in NHS campuses. In 2001²⁴, DH said that people in NHS residential campuses should have the chance to move, and in 2006²⁵, we committed to closing all campuses by 2010. Therefore, by delivering on this policy, we will have closed the service settings where there is the greatest misuse of psychiatric medication in people with learning disabilities.

Recommendation 4c: Positively promote healthy living, including through options for diet and exercise, in their own services and raise expectations of good health including by access to expert patient programmes, so people can take charge of their own health

We agree that it is important that people with learning disability or mental health problem should be empowered and supported to make healthier lifestyle choices. The Expert Patients programme for people with mental health problems is currently being tested, and should be available nationally in 2007 (see response to 1k). The equivalent programme for people with learning disabilities is yet to be tested, but this will happen in 2007. Other programmes, such as Health Trainers and LifeCheck also support people to take control of their own health and well-being.

²⁴ 'Valuing People' white paper, 2001

²⁵ 'Our Health, Our Care, Our Say' white paper, January 2006

Recommendation 5:

Performance management, inspection and scrutiny bodies should require action by commissioners and providers to close gaps of inequality

Tackling health inequalities is a priority for Government and PCTs when they are commissioning health services.

Recommendation 5a: Support boards in their governance role, to take a strategic approach to disability equality

We agree that boards must set an example of equality, and ensure that the highest standards are met in the service they oversee. We have recently published guidance to help NHS board members understand and comply with their legal obligations²⁶.

DH will work with the Appointments Commission to raise the profile of disability equality in the recruitment, training and appraisal of NHS board members. Specifically, we wish to ensure that people are not excluded from serving as non-executive directors on PCT boards because of their learning disability or mental health problem. We are also currently developing a programme to improve commissioning capability, both in health and social care, and we will ensure that a strategic approach to disability equality is included in this work.

Recommendation 5b: Ensure capacity and expertise in learning disability and mental health are established for effective commissioning

We agree that effective commissioning is of central importance. For strengthening capacity in learning disability and mental health commissioning see response to 2g. See also 5c below.

Recommendation 5c: Strengthen, scrutinise and inspect commissioning, including on how local assessment of the needs of people with learning disabilities and/or mental health problems is used actively to commission effective service models and to drive up quality and access

We agree that commissioners and the services they commission need to deliver quality care and be accountable to service users. PCT and local government commissioners are accountable for appropriate and effective commissioning. Good joint strategic needs assessments will provide a much better foundation for commissioning health and well-being services that meet the needs of all parts of the community. Publication of PCT prospectuses will ensure the local community has information on how health service resources are used, and Local Area Agreements will hold all local partners accountable for the delivery of targets on specific local priorities.

²⁶ "Equality and Human Rights in the NHS: A guide for NHS Boards", December 2006

The NHS has recently been reminded of their responsibilities in delivering good quality learning disability services (see response to 2g). The Parliamentary Undersecretary of State for Care Services committed in the House of Commons²⁷ to ensuring that the abuse that occurred in Cornwall does not happen again. The statement committed DH to bringing forward proposals for strengthening learning disability commissioning. In addition, the Healthcare Commission is currently piloting an audit of specialist learning disability services, to be carried out nationally from January 2007. SHAs must assure themselves of the quality of learning disability services following any actions arising from the audit, and ensure they have an understanding of PCT commissioning practices with regard to services for people with learning disabilities in their area.

DH will be publishing guidance to clarify the processes for the commissioning of Specialist Learning Disability Services, which will help to set out clearer roles and responsibilities – see response to 4.

Recommendation 5d: Inspect services against standards for primary care access and healthy living, with user involvement in inspection

We agree that services should be monitored, and that we should address progress in closing gaps of inequality. As part of the cross-Government agenda to modernise regulation and inspection, DH is consulting on system regulation for the health and adult social care sector. We will consider whether services should be inspected against standards for primary care access and healthy living in the context of the role and functions of the future regulator which result from the consultation.

DH is working with the National Patient Safety Agency to consider taking forward work on good practice in communication and safety for staff in mainstream hospital services on specific issues for and needs of people who use specialist services.

The Commission for Social Care Inspection, which currently inspects adult social care services, employs service users or ‘experts by experience’ on their inspections. The Healthcare Commission, which inspects health services, are discussing the possibility of involving service users with the DRC.

Recommendation 5e: Assess progress in closing gaps of inequality

We agree that inspection and scrutiny bodies may have a role to play in monitoring inequalities. DH will discuss the role that inspection and scrutiny bodies can play in monitoring and encouraging progress. See responses to recommendations 1p, 2g and 3f.

²⁷ On 6th November 2006, Ivan Lewis, Parliamentary Undersecretary of State for Care Services delivered a Written Ministerial Statement in the House of Commons

Recommendation 6:

Professional bodies, standard setting and good practice organisations should:

Recommendation 6a: Improve the evidence base, guidelines and indicators to support commissioners and providers to 'close gaps'. The Royal Colleges, British Medical Association, National Institute for Clinical Excellence (NICE), National Primary Care Development Team, Public Health Observatories, Case Services Improvement Partnership (CSIP), National Patient Safety Agency (NPSA), and other relevant good practice organisations have key roles. Public Health Observatories should appoint a national lead for disability equality

We agree that more work needs to be done, with the relevant organisations, to strengthen the ability of commissioners and providers to respond appropriately to the needs of those with learning disabilities and/or a mental health problem.

All DH research must respect the diversity of society, and take account of equality issues in its design, undertaking and reporting. The body of research evidence available to policy makers should reflect the diversity of the population. DH Research and Development has invested over a number of years to develop the evidence base in the areas of learning disability and mental health. For example, a new research initiative (costing £2m) was launched in 2000 focusing on the lives and experiences of people with learning disabilities. It was developed in consultation with the Department's Learning Disability Advisory Group, which includes service users, families, academics, NHS professionals and local authority managers. The initiative is informing the implementation and outcome of the 'Valuing People' white paper.

The majority of the organisations listed in the recommendation have been mentioned elsewhere in our response. We recognise the importance of engaging with the appropriate organisations, and are committed to continuing to do so as we take this work forward.

Recommendation 6b: Integrate the needs of people with learning disabilities and/or mental health problems into relevant clinical guidelines, standards and good practice guides, for instance on CHD, diabetes, obesity and smoking

We agree that clinical guidelines need to be fully inclusive, and address the needs of people with learning disabilities and/or mental health problems. We will discuss with NICE whether an audit or review of clinical guidelines is appropriate.

Recommendation 6c: Develop specific guidelines where needed. For instance NICE could provide guidance to primary care on the content of

regular health checks and (with the British National Formulary) on the physical health monitoring required for people taking specific psychiatric medication. The Association of Medical Secretaries, Practice Managers, Administrators and Receptionists (AMSPAR), the Practice Managers' Network and others could draw up guidance with user groups to support implementation of reasonable adjustments in primary care

We agree that further work may be helpful to develop specific guidelines in a number of areas. DH will explore the possibilities, and work with and support organisations to do this.

Recommendation 7:

In taking forward the recommendations it will be important to address the needs of different populations including people from different minority ethnic communities and age bands in order to work to close gaps of inequality by race, age, gender, sexual orientation and other factors in line with current and planned legislation. Our overall recommendations to strengthen strategic needs assessment and commissioning for the whole population and to personalise services are complemented by some more specific proposals for different populations.

We agree that local commissioning needs to be flexible to respond to the needs of different populations. We do not intend to respond to all these further recommendations in detail here.

A partial equality impact assessment of the Commissioning Framework for Health and Wellbeing (see response 1a) is currently out for consultation (together with the Framework itself)²⁸ and a full assessment will be completed following the three month consultation process.

The Framework will strengthen Strategic Needs Assessment (SNA) and commissioning by:

- sharing good practice on commissioning health and well-being, including SNA
- proposing minimum standards for SNA
- proposing substantial and sustained investment in building commissioner capability

²⁸ The partial equality impact assessment is available at www.commissioning.csip.org.uk

Annex A: Action plan

ACTION	Rec.	By when?	By who?
Publish 'Commissioning Framework for Health & Well-being'	1a	Achieved - March 2007	Demand-side reform, DH
Write to PCTs to remind them of their obligations, including access to screening services	1c	2007	Commissioning directorate
Issue further advice to PCTs and practices on registration of patients without a permanent address	1e	2007	Primary care access, DH
Develop further guidance on charges for primary care for care home residents	1e	2007	Primary care access, DH
Work with stakeholders to consider how to address diagnostic overshadowing	1f	2007	Education and training, DH
Review appraisals systems	1f	2007	Education and training, DH
Explore ways to increase the capacity of self advocacy groups to run training for NHS staff	1f	2007	Office of the National Director for Learning Disability (ONDLD), DH
Publish the national framework for disability education	1g	2007	Education and training, DH
Write to each of the health professions regulatory bodies about the DRC report	1g	2007	Education and training, DH
Work with the professional bodies to address disability equality in undergraduate curricula	1g	2007	Education and training, DH
Publish new guidance on the Care Programmes Approach	1i	2007	Mental health team, DH & CSIP
Publish new guidance on Health Action Plans for people with learning disabilities	1k, 4a	2007	ONDLD, DH
Building on and sharing good practice	1k	2007	ONDLD, DH
Encourage the development of Total Communication Networks	1k	2007	ONDLD, DH
Develop Learning Disability specific supplement to DED guidance	1l	2007	ONDLD & Equality and Human Rights, DH
Explore the possibility of a training induction package on the DED for NHS staff	1l	2007	ONDLD & Equality and Human Rights, DH
Revise the Departments systems and processes to ensure the Disability Equality	1m	2007	Equality and Human Rights, DH

Scheme is used			
Commission research on barriers to strong involvement of local Partnership Boards	2b	Early 2007	Learning Disability Task Force
Discuss obtaining data on causes of death of people in contact with mental health and learning disability services	2g	2007	Mental Health Team, DH & ONS
Explore the possibility of mandating specific improvements in equity of access	3a	2007	Primary care access, DH & NHS Employers
Ensure doctors have access to the information they need on the physical effects of psychiatric medication	3c, 4b	2007	Mental Health team, DH & Royal Colleges
Stress the importance of including all groups in LINks through guidance	3d	2007	Public and Patient Involvement, DH
Explore raising the priority of ensuring people removed or refused access from a GPs list get written reasons why	3e	2007	Primary care access, DH and SHAs
Discuss including learning disability as a subset on Healthcare Commission surveys	3f	2007	Public and Patient Involvement, DH
Publish guidance on commissioning of 'Specialist Disability Services'	4	2007	ONDLD, DH
Work to raise the profile of disability equality in the recruitment, training and appraisal of board members	5a	2007	Commissioning and PCT development, DH
Consider whether services should be inspected against standards for primary care access and healthy living, as part of consultation on role and function of future regulators	5d	2007	Standards and Healthcare Commission Relations, DH
Consider taking forward good practice on communication and safety for staff in mainstream hospital services regarding people who use specialist services	5d	2007	Mental health team, DH & National Patient Safety Agency
Discuss the role that inspection and scrutiny bodies can play in monitoring and encouraging progress	5d	2007	Mental health team
Discuss whether an audit or review of clinical guidelines is appropriate	6b	2007	Primary care and ONDLD, DH and NICE
Explore where additional guidelines are needed to support commissioners and providers in delivering services that are fully inclusive	6c	2007	Primary care and ONDLD, DH with NICE, AMSPAR and others as necessary